



Fife Dementia Strategy Review

Workshop Feedback

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[24 November 2021]

Fife Health & Social Care Partnership Supporting the people of Fife together





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1. Introduction and Methodology

Fife Health and Social Care Partnership have completed the collection of feedback through engagement activities with those who live with dementia, those who support someone living with dementia including paid and unpaid carers.

Fife Health and Social Care Partnership launched the consultation on 20 September 2021.

The Public Engagement Team have facilitated 12 face to face workshops throughout Fife as well as hosting 2 on-line workshops with various stakeholders seeking their views and opinions to provide a fair representation of Fife's dementia needs. The face-to-face sessions followed the structure of participation via conversation and interactive worksheets directed by 5 'themes' that would encapsulate the individuals' dementia journey from pre diagnosis to the now:

- What I enjoy in my life right now
- What has gone well
- What is important to me
- What could be improved
- · What is missing

Participants were encouraged to write down their thoughts/views/opinions on the interactive worksheets. One participant requested that information sent via email to the Public Engagement Team be recorded as feedback as part of the engagement and participation process. These points were duly recorded as requested. The feedback was then recorded and grouped into the following categories that emerged through discussion:

- Community Groups
- Information
- Benefits
- Transport
- Diagnosis
- Family
- Wellbeing
- Care and Support
- Housing/Other





The online sessions followed the same structure as the face-to-face workshops. Participants engaged in open discussion, had use of the chat box function on Teams and notes were taken by the Public Engagement Team to record opinions and views for feedback to be included in the response.

Feedback within this report has been collected via each of the methods described above. Participants were also informed of the on-line consultation/survey that was being launched on 09 November 2021.

As public reference group the existing group STAND (Striving Towards A New Day) which is a peer support group for those with early onset dementia was used. This group tested our approach for suitability and sense test purposes. Representatives from this group were also present at various sessions to support facilitation and to "oversee" the workshops were run accordingly and fairly representing the citizens of Fife. Funding for this purpose was donated by Innovations in Dementia.

In total 16 workshops were planned throughout Fife (Appendix 1) 4 were cancelled due to no participant registrations and 3 on-line workshops were planned with 1 being cancelled due to no participant registrations.



2. Workshop Feedback

The findings recorded below are from the face-to-face interactive workshops and are based on direct feedback from participants who attended the sessions and are categorised for analysis purposes using the five main themes as set out above. The groups comprised of the following: - members from STAND; those who live with early onset dementia; those who live with dementia; unpaid carers and paid carers/support workers as well as one individual who a personal interest in community research on the subject of dementia.

2A: Theme - What I Enjoy in My Life Right Now

Participants were asked to discuss what they enjoy in their lives right now. Responses created topics through conversation with most of the feedback on this theme promoting the value of community groups where individuals felt involved and had a sense of purpose. Participants across most groups conveyed the importance of community groups as a great community asset where support, friendship and advice could be sought.

Community Groups

Participants discussed in-depth with enthusiasm the value of community groups.

"Self-confidence has returned. Proud to provide help and support to others".

"Doing activites that I am good at" (skilled joiner)

"Using previous skills to research dementia which has helped me - talking to other people helps me cope - gives me a constructive use of time - without it I would sink".

"Dementia Friendly Community"

"I love dropping my dad off at Later Life Choices - when I pick him up I know he had a great time"

"Great friendship through peer support group (STAND)

"I love this group - the bus comes to get me - without it I would be lost"



Family and Friends

Participants discussed the importance of family and friends recognising the value they bring to each other's lives.



"The company of daughters to talk to - they always include their dad"

"Being with friends is important to me"

"Time spent with my husband"

Health and Well-being

Participants highlighted during discussion activities that promoted their health and well-being.

"Socialising and have a cup and a biscuit"

"Healthy walks outside/arm chair exercises"

"Staying active for mental well-being"

"Meeting every week to help me understand new way of living" (at community group)

"My garden and being outside"

"Doing physical activities while I am still able"

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Care and Support

Participants during conversation on what they enjoyed in their lives highlighted how support whether it be receiving support or giving support had a positive impact on their lives.



"My befriender and the time I spend with him"

"Being a support mechanism"

The general feeling when considering what participants enjoyed in their lives was that without community groups many would be at a loss. Those living with dementia highlighted the importance of creating friendships, having the opportunity to partake in activities that were of interest to them, having a sense of being valued and understood were vital elements of enjoying life – all of which were found within a community group setting.

Participants also discussed the importance of family support and friendships out with community group settings as key factors in living an enjoyable life.

It is also worth noting that both those living with dementia and those who supported someone living with dementia gained enjoyment from being a support mechanism to their loved ones and others. The value of having a befriender was also discussed as a key component to enjoying life.

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2B: Theme - What Has Gone Well

Participants were asked to consider what has gone well in their lives from the point of diagnosis until now. This theme generated a more varied response with participants sharing their views and experiences over a wider range of topics. The main topics in theme focussed on community groups and support with some discussion around family, information, and diagnosis.

Community Groups

As with the previous topic, community groups stood out as something that had gone well in the lives of participants – again the general feeling across the groups was of community groups being invaluable particularly with regards to learning from others experience and gaining support.

"STAND's progress is key because its welcome extends to people before and after diagnosis. This is crucial given the adverse impact of Fife's assessment backlog on people, communities and the economy" (unpaid community researcher)

"Knowledge of dementia was increased - speaking to others/sharing tips"

"Volunteer organisations are good to help you to find out about other places"

"Community Groups - couldn't cope without it - talking to people that understand"

"As a carer it was speaking to people that helped me - you get to listen to people with experience"

"Social Groups in the community - Later Life Choices is Fanstastic"

"Fife Council reslience and community groups have been fantastic throughout COVID - please continue with these invaluable services!"

"Conversations with others helped us make sense of mum's condition - in a state of mourning for loss of something/someone that is still there - her own hopes and dreams"



Family and Friends

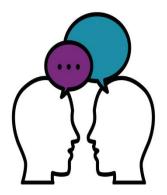
Participants through discussion revealed that in many cases relationships with family members became closer. The importance of family and support workers creating positive relationships was also highlighted as key in supporting someone with dementia.

"good family support - we took turns" (unpaid carer)

"closer relationships with family/friends that support/care for me"

"great relationship with the family helped me support the person" (paid support worker)

"Those that had family/carers at home - helped them (those with dementia) get on-line"



"People seem to listen more from friends and family rather than from professionals – we need more peer groups for this"



Care and Support

Participants during conversation highlighted that support from family, friends, paid/unpaid carers along with legal support had a positive impact on how their lives living. Conversation generated around this topic gave a diverse range of views and experience offering insight into the positive impact of paid support services (both private and public funded) within the community.

"We had private help who popped in at night and 4 mornings per week - my dad paid for this"

"At the early signs we went to a solicitor to get power of attorney - what a difference that made"

"Insulin given by nurses every morning - helpful to myself and husband just seeing someone else"

"Viewforth Day Services at Queen Margaret was brilliant" (stopped because of COVID)

"Care staff who showed terrific compassion" (towards father in resdiential care)

"By the carer being there - just that hour gives the husband a break" (paid support worker)

"The 45 min service I get at home for my husband is really good"

"Good support from occupational therapy team"

"When people do come through the door they are getting really good services and activities - cognitive stimulation" (paid day service staff)

"Our outreach support service - we provide person centred 1 to 1 support - they really benefit from that" (paid day service staff)

"I get carers to help me shower/take meds - I over dozed myself a long time ago (by accident) ...I couldn't do without my carers they keep me safe"

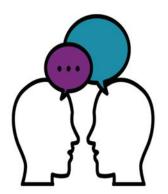
"Encouraging more people to use on-line services and new technology - especially during the pandemic"

"We learned more about service users when we did 1 to 1 home visits when restrictions eased - in a group environment you don't get that - the one silver lining" - day services staff



Information

Participants discussed what went well when considering information on dementia and support.



"A lot of good support/help/advice comes from word of mouth"

"Fife Carer's were good – they helped me find out about benefits"

"Technology can be helpful – it's about finding out what works for you"

Diagnosis

Participants during conversation were asked to think about what went well with the diagnosis process at the start of their dementia journey. The feedback evidenced that those living with early onset dementia had an overall positive experience during the diagnostic stage. Interestingly participants who were diagnosed later in years reported that their experience was less positive, and this is evidenced under the theme "what could be improved".

"I saw specialists from the start, so my medical experience has been good with my body and mind but as a human socially I didn't exist"

"Post diagnostic support"

"Pre Diagnosis and Post Diagnosis Support" (younger onset)



2C: Theme - What is Important to Me

Participants were encouraged to discuss what is important to them. This theme produced a great deal of discussion highlighting inclusion and general wellbeing. Care and support were discussed with emphasis on person centred consistent support being crucial to those living with dementia. Community groups again were recognised as being an invaluable community asset.

Community Groups

Community groups were highlighted by many participants as an important part of their lives particularly with regards to socialising and having informal support networks.



"STAND's progress is key, because its welcome extends to people, before and after diagnosis. This is crucial given the adverse impact of Fife's assessment backlog on people, communities and the economy". (individual with personal interest in community research)

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Wellbeing

Discussion around this topic was very much focused on individuals being treated as individuals with their own needs, feelings and thoughts, with conversation bringing to the fore that being an unpaid carer can affect relationships as family "roles" have changed.



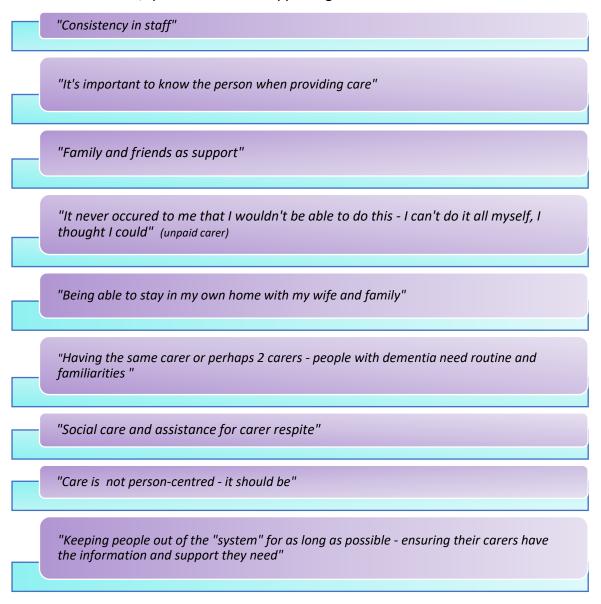
"I want to be a son to my dad.... not his carer who is the bad guy and have to do his private care. I need some help, so me and my dad spend time together as father and son"

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Care and Support

Care and support were recognised as being important by participants with an emphasis placed on consistency of carers and having a knowledge of the person who is receiving support. It was evident that both those providing informal care and support were keen to continue with this role and to support their loved one at home - consistency and carer support are required to enable this to continue. Recognition was given to the importance of the dementia nurse/specialist team in supporting individuals and their families.



"I strongly encourage Fife to ensure that there is always someone in the Dementia Nurse post. This is key in taking people from diagnosis to bereavement, and in providing essential help-line and other support" – indivudal with personal interest in community research

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2D – Theme: What Could be Improved

Participants in this theme generated detailed discussion looking at various elements of care and support. A vast range of feedback was collected taking opinions and views from the start of individuals' dementia journey through to where people are at now. Discussion was also lively when considering the diagnosis experience. Participants also highlighted that information and access to benefits needs to be improved. Transport was also discussed during this theme and although public transport is available it is considered high risk to those with dementia travelling alone.

Care and Support

The general feeling across the participant groups was that care and support packages are too difficult to access; there is a need to involve family members more; day care services appear to be reducing; consistency in care and support is required along with an increased awareness of dementia; respite and flexible support for unpaid carers needs to be improved and post diagnostic support could be improved for those living with dementia.





"We heard a few months later (after diagnosis) from Whytemans Brae - twice we had visits then this stopped - no input for 2.5 years - 1 visit from the post diagnosis dementia team - then COIVD came - we were then taken off the books"

"Family need to be involved not kept out of the loop - they need to know the family"

"You need a social work assessment to access respite - if I don't get this I will be dead! I would pay but don't know where to go - I'm not confident to choose"

"There is a lack of awareness on how to support someone with dementia - capacity is compromised - 'the right to choose' sometimes has been overlooked"

"Communication between services - seems to be a lack of attention to detail when delivering the working package"

"End of life care"

"Staff knew he had dementia but didn't know the implications of it - he had ran out of milk - she said "I told him that he needed milk yesterday"

"Medical teams in general wards need to have awareness of dementia and how to deal with it"

"Accessiblity of services (for unpaid carers) - flexibility outwith working hours"

"Specialist dementia day care seems to have taken a step back ...transport has been cut, personal care has been cut, numbers services are able to support is now minimal"

"There seems to be a lack of services in rural areas - not the whole of Fife is covered"

"Social work involvement wasn't great - it was like a tick box exercise"

"Care at Home is a big issue - there are lots of people waiting - for those that are getting it they are getting it later, so they are missing out on our service - and that its crazy - it seems to be disjointed" - day service staff member

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Diagnosis

Participants were encouraged to share their views and experience of the diagnosis process on their dementia journey. A common theme within this topic was that of older persons being diagnosed with dementia felt that that diagnosis process needs to be improved to enable access to medication and support. It was conveyed that some participants found doctors/psychiatrists were hesitant to diagnose dementia which in turn held up accessing appropriate care and support which had a detrimental effect on their overall well-being. It was felt across all groups that doctors and other professionals should listen to the family/carers more as it is them who notice the difference/decline in the individual the most. However, it must be noted that those who live with early onset dementia found the diagnosis process and post support to be a more positive experience but, in some cases, they too experienced hesitation from the medical field in making an actual diagnosis.

"Doctors need to listen more to the individual i.e. more knowledge of people living with younger onset of dementia"

"Psychiatrist was hestitant in diagnosing - it was my wife who saw the signs herself in her 40s - it was in her 60s until she was diagnosed"

"Most professionals don't recognise it as a disease"

"GPs must listen to carers/family members - as they are the ones who see the change"

"I am angry about everything - it took 3 years to get diagnosis - that's 3 years of missed medication"

"Early diagnosis - there was a lack of support for men of a working age (possibly women too)

"GPs could be more responsive from early stages"

"People with Deaf(ness) are often misdiagnosed as often it is put down to hearing issues not dementia"

"When diagnosed it's great you get the meds but it's the wait for diagnosis"

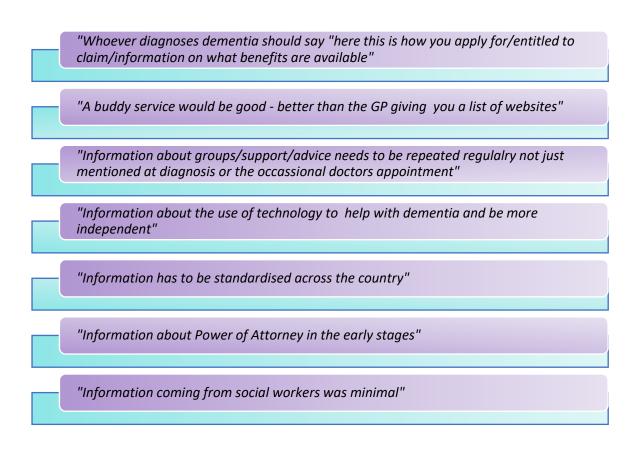
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"Post diagnostic teams are short staffed and can't get around everyone - it's not a lack of will/want they are just so short staffed - it's an amazing template that isn't working as they are short staffed" - day service staff

Information

A common theme throughout the various workshops was that of information. Participants fed back a variety of experience and views on this matter. Some reported that information was patchy; not consistent; difficult to find with some participants noting that more information should be available either at point of diagnosis or soon after.



"At one point when you got a diagnosis you were referred to post diagnostic team - supposed to give out info - that support was for 1 year - if delay in diagnosis where else do you get that info?" - day services staff

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Benefits

During the workshops access to and information about benefits was an area that was felt by all that could be improved. Participants fed back that applying for and being assessed for self-directed support was a complicated process. There was a strong feeling that being able to have access to self-directed support would enable a greater level of independence and could prevent crisis situations. Some participants noted that they did not know what benefits they may be entitled to claim.



"A lot of people still don't know they can access certain benefits - there are so many things people still don't know they are entitled to" - day service staff

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Transport

Participants recognise that transport is a key component to supporting them to live an independent life, access services and support. The general feeling was that in rural areas participants had to travel to get support. Day services staff fed back that due to social distancing measures they were restricted as to how many service users could access their transport to attend the group setting. Participants also expressed that if they were able to access transport to go to an activity their unpaid carer could have a break.



"Transport is there but it's high risk for people with dementia on their own"

FHSCP Dementia Project Manager

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2E: Theme – What is Missing

Participants during the workshops were asked what was missing from their point of view to help them with their lives on their dementia journey. When considering this theme participants fed back in detail about Care and Support Services and Information as being areas where there were important elements missing that would have a positive impact on living with dementia/supporting someone living with dementia. Comments were also noted regarding the diagnosis process, benefits and housing.

Care and Support

When considering what was missing with care and support a large amount of conversation was generated. Participants identified that day services appeared to be reducing due to restriction with numbers of people that could be supported were limited. It was also identified that day care services were not suitable for all and that other support should be available. Access to a specialist/nurse team was also thought to be missing for those over 65. Unpaid carers identified that they would benefit from training and where required support overnight - both of which would enable the individual with dementia to remain at home longer. Participants also felt that they would benefit from having a "caseworker" who would support them throughout their time living with and supporting someone with dementia – someone to guide them to information and services. One participant also raised the relevant point of language (BSL) being supported when someone was moved into a care home.





"Day services for those that cannot do thier own personal care (we are not funded for that) "Day care isn't for everyone there has to be alternative support available to people" "We've taken a step back..we are not providing transport, we are not providing personal care and the numbers we can support is minimal - it's a big issue" (day services staff) "Moving and handling training for unpaid carers" (unpaid carer) "Lack of continuity in care" "We need 24 hour care at home" "Home support prior to moving into care (lack of)" "We need access to a specialist nurse/service - those under 65 get this -but those over 65 are age-discrmintated" "A case worker - connection with services" "There should be dementia training in every GP practice - from receptionists to GPs" "It's important that if a Deaf person is moved into a care home that supporting their language is crucial "

"24 hour care at home is needed - it's getting up through the night - if someone is double incontinent this is how they end up in a care home" - unpaid carer

Diagnosis

Participants when considering what was missing from the diagnosis process commented that dementia should be acknowledged as a long-term terminal illness, commenting that it was felt more investigation was required at the start of the diagnosis process. A main point that has been commented previously was that of the point of earlier assessment for diagnosing dementia.

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"Dementia should be acknowledged as a long-term terminal illness"

"There is a lack of investigation at the start of diagnosis"

"Why are we not assessed earlier?"

Information

The main feeling around information from participants was that of information should be easier to access and ideally there should be one place to go for information that will help support and guide people to what support, service and benefits are available to them. Participants also noted that information regarding power of attorney requires specialist advice. One participant also mentioned that there was a lack of information in BSL regarding dementia and services and support that are available.

"Not enough in communties for early stages and pre-diagnosis"

"Dementia friendly places - a list on Fife Council website"

"No BSL info on dementia/where to go"

"No transparent info on power of attorney - specialist advice needed"

"Carers never receive any information or guidance as to what support is available

"Should be one port of call where you get all the information - or given a number to say 'we are here to help you'" - day service staff



Benefits

Participants felt that access self-directed support payments were missing and that by having this independence could be improved.



"Everyone getting SDS now - would make such a huge difference rather than waiting to be assessed as critical"

"Awareness of self-directed support"

"SDS would enable so much more independence"

Housing

During the workshops only a few participants raised the topic of housing. However, there were a couple of statements from participants that are worth noting that raise the point of suitable housing and funding to adaptations.

"I can't find available housing options to be closer to friends or a bus route. What are local options for rented and owned elderly accommodation, day centre and care home" - unpaid community researcher

"We've adapted our house for the future - paid for this ourselves as there was no funding"

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3. Conclusion

To conclude the findings of this report, participants identified the importance of community groups as having a positive effect on their lives. The ability to meet with others for informal peer support was highlighted along with the opportunities to create lasting friendships and reducing social isolation. It was noted that for more people to access community groups that transport and/or a befriender/support worker would be a great benefit. Participants also acknowledged that family and friends and maintaining good relationships were vital with some reporting an increase in closeness since diagnosis.

Physical activity was noted as a key component for maintain good health and wellbeing, however without the support of others there is a risk that the individual living with dementia may not be able to attend activities to meet this need.

Participants discussed the impact of family "roles" changing since diagnosis and becoming an unpaid carer. It was identified via the sessions that the majority of unpaid carers want to offer care and support to those living with dementia but in order to be able to continue to do so support from services was required. Unpaid carers report that many of those living with dementia are awaiting a package of care with some reporting that having access to self-directed support would alleviate some of the pressures of unpaid carers. The general feeling was that access to self-directed support should be easier and should be allocated before crisis situations for early intervention and to maintain, and in some cases increase independence.

Participants fed back that day services offered valuable support for those living with dementia but due to the current pandemic services have been restricted in the numbers that can be supported. Day services were viewed by participants as a valuable community asset and individuals who wished to attend day services should be able to do so when not assessed as being critical. It was recognised that day services are not suitable for everyone and in such cases there should be suitable alternative activities/groups available. Although participants could identify positives that arose from the pandemic – it was stated that there is no alternative to face-to-face support.

Information regarding dementia and support/services available generated a lot of discussion points. Information should be consistent and standardised, easier to access and ideally there should be one point of contact for information from the point of diagnosis right through to the end of someone's dementia journey. Participants highlighted that specialist information regarding power of attorney should be easier to access.

When considering the diagnosis process, participants stated that actual diagnosis should be quicker with some participants noting hesitation from consultants/doctors in giving a





diagnosis. Feedback gathered stated that participants felt that GPs and medical practices should be better trained in dementia and dementia awareness and that family members should be more involved. Participants expressed that a delay in diagnosis meant a delay in receiving medication which is crucial for many who live with dementia.

Discussion around Care and Support generated a large amount of discussion with the main themes across participant groups stating care and support packages are too difficult to access; family members need to be involved; consistency is required along with an increased awareness of dementia by those who deliver care and support. A need for respite and flexible support for unpaid carers was identified as a required improvement. However, it must be noted that those who do receive a package were mainly positive. Participants fed back that it is important for carers to be compassionate and build good working relationships with family. It was highlighted that there is a need for 24hour care within the home setting to reduce the need for admission to care homes and to enable unpaid carers to continue to provide care and support. When considering housing and adaptations it was commented on that provision of housing nearer to community service and bus stops appears to be lacking. One participant commented that they had paid for adaptations to their home as no funding was available.

Accessibility and availability of transport was discussed amongst participants. Transport to take individuals to activities would be of great benefit to both the individual living with dementia and to their unpaid carer.

It is recommended that consideration be given to all the above points for inclusion and contribution to Fife's Dementia Strategy Review.

4. Appendix 1

Timetable of Workshops

Date	Location	No Participants	Comments
20/09/2021	Kennoway	11	STAND members
22/09/2021	Tayport	4	
23/09/2021	St Andrews	4	
27/09/2021	Anstruther	1	

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05/10/2021	Kincardine	Cancelled	0 registrations
07/10/2021	Inverkeithing	Cancelled	0 registrations
08/10/2021	Kinghorn	10	
11/10/2021	Kennoway	4	
12/10/2021	Leven	Cancelled	2 reg participants
			cancelled
22/10/2021	Glenrothes	2	
26/10/2021	Dunfermline	2	
27/10/2021	Cowdenbeath	2	
28/10/2021	Cupar	5	
29/10/2021	Dunfermline	Cancelled	1 reg participant
			cancelled
02/11/2021	MS Teams	2	
03/11/2021	MS Teams	3	Day services staff
04/11/2021	MS Teams	Cancelled	0 registrations
09/11/2021	Kirkcaldy	1	Individual with
			personal interest in
			community research
15/11/2021	Glenrothes	10	Later Life Choices
			group
Totals		61	